

Massachusetts Department of Public Health  
Pediatric Palliative Care Network  
Operational Program Standards

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## A. About the Pediatric Palliative Care Program

In April 2006, Governor Mitt Romney signed into law “An Act Providing Access to Affordable, Quality, and Accountable Care.” In Section 2A, 4590-1503, the Pediatric Palliative Care Program was established in Section 24K of Chapter 111 of the General Laws. The program is administered by the Massachusetts Department of Public Health, Division for Perinatal, Early Childhood and Special Health Needs.

The Pediatric Palliative Care (PPCN) program is designed to complement existing services to meet the needs of eligible children with life-limiting illnesses and their families or guardians. For the most part, these services are provided in the home and are appropriate for children with a wide range of life-limiting illnesses, even when cure remains a possibility. The PPCN program supports the child and family with services designed to achieve an improved quality of life by meeting the physical, emotional and spiritual needs experienced during the course of illness, death and bereavement.

As aptly described by the Canadian Hospice Palliative Care Association (2006), pediatric palliative care “is designed to enhance choice, relieve suffering, and ensure the best quality of care during living, dying and grieving.” The Massachusetts PPCN program supports the child and family to accomplish these goals in accordance with their values, needs and preferences by providing access to a full range of consultative and direct care palliative services. The services complement those rendered by the child’s primary care provider who retains professional responsibility for the child’s plan of care. Examples of these services include but are not limited to skilled pain and symptom management, counseling for the child and family, spiritual care, advance care planning, referrals to other community services, short-term respite care, and bereavement care for the family.

## B. Definitions

For the purpose of this document, the following definitions are used.

**Life-Limiting Conditions:** Conditions where premature death is likely or expected. Conditions appropriate for pediatric palliative care include but are not limited to :

- Those children who have conditions from which they could die, e.g.: cancer
- Those children who have progressive conditions from which they are certain to die, e.g.: neurodegenerative diseases like Tay-Sachs, Spinal muscular atrophy (SMA), Duchene’s Muscular Dystrophy, etc.
- Those children who have congenital or genetic conditions that are likely to cause their death, e.g.: Trisomy 13, anencephaly

- Those children who have had a traumatic injury or event which causes them to be fragile and at risk for death, e.g.: severe birth asphyxia, accidental trauma, shaken baby syndrome

**Pediatric Palliative Care:** An active and total approach to care, embracing physical, emotional, social and spiritual elements, for children who face a progressive, life-threatening condition and their families. It focuses on quality of life for the child and support for the family. It also includes the management of distressing symptoms, provision of respite, and care through death and bereavement.

**Pediatric/child:** Children and youth under 19 years old.

**Primary Care Provider:** A primary care provider is the pediatrician, other physician, nurse practitioner, agency, nurse or case manager who has professional responsibility for the care of the child and family.

**Family:** Families may include but are not limited to: parents, step-parents, siblings, legal guardians, household members, grandparents, relatives and friends regularly providing care for the child, and other persons defined as "family" by the child.

### C. Core Principles of the Massachusetts PPCN Program

**Pain and Symptom Management.** The child should be as symptom-free as possible. Pain and/or other symptoms should be managed to achieve the greatest possible level of comfort.

**Family-Centered Care.** The unit of care is the child and family, with the family defined as those individuals with whom the child has a significant relationship. Decisions about care are made by the child, to the extent the child is able, and family, aided by professional caregivers. PPCN respects and maintains the dignity and wishes of each child and his or her family.

**Interdisciplinary Approach.** PPCN services are planned and delivered by an interdisciplinary team. Members of the hospice's interdisciplinary team must include a nurse, social worker, chaplain, and volunteers under professional supervision. PPCN services are both consultative and direct.

**Collaboration with Pediatric Providers.** PPCN and participating hospices recognize the importance of the primary care provider/child relationship as integral to the plan of care. Respect is shown for the role and needs of other providers caring for the child and family.

**Sensitivity to Culture-Specific Needs.** The cultural background, concerns and needs of the family are elicited, documented and addressed by the PPCN staff. Translation services are available for non-English speaking families.

### D. Eligibility for Services

- All children less than 19 years old, who are determined by a physician to have a potentially life-limiting illness, are eligible for the program.

- All life-limiting diagnoses are included. PPCN providers retain on file a DPH-approved form, completed and signed by the referring licensed Massachusetts physician, dated by the physician, including identifying information about the child, including birth date, and documentation of the child's life-limiting condition. Transfer by consent to the hospice of physician records containing the same information may substitute for the form. Documentation should be on file within 2 weeks of referral.
- There are no restrictions as to the life expectancy of the child.
- Children in the PPCN program may continue to receive care directed at cure.
- Admission to PPCN does not preclude the child and family from treatment choices or hopeful, supportive therapies
- Children are admitted to the program without regard for diagnosis, gender, race, creed, age or ability to pay.
- When considering the appropriateness of a referral, discernment should also be given to recent medical crises and activity, i.e. hospitalizations, ER visits, frequency and severity of respiratory events, and more advanced stage of illness, etc. Efforts should be made to identify those children at highest risk.

## E. Service Providers

### Required Provider (Vendor) Qualifications

- The hospice program is licensed under section 57D by the Massachusetts Department of Public Health, and is Medicare and Medicaid certified.
- Qualified individuals are designated to lead, coordinate and staff PPCN services at the participating hospice program.
- The hospice identifies a physician or nurse with experience in pediatric palliative care medicine, to provide consultation to the Interdisciplinary Team (IDT).
- The hospice provides to DPH documentation of recent experience and competency in pediatrics of the nurse, social worker, chaplain and bereavement coordinator who will provide care.
- For hospices with no recent pediatric experience, there must be a training plan to complete competencies in pediatric palliative care for direct care staff.
- The hospice provides documentation of attendance at DPH-sponsored PPCN training programs and other related educational conferences and courses.

### PPCN Staff Credentials

- PPCN physicians, registered nurses and social workers must be licensed in the Commonwealth of Massachusetts
- PPCN staff must be knowledgeable, and receive on-going training, for prognostication, signs and symptoms of imminent death, associated care and support for needs of children and their families before and after the death, including age-specific physical and psychological syndromes, opportunities for growth, normal and aberrant grief and bereavement processes.
- PPCN Volunteers shall be under the professional supervision of the hospice's Volunteer Coordinator. Completion of specific training in pediatric palliative care prior to beginning volunteer services must be documented.
- Support for training and education is available to the PPCN staff from DPH.

## Contracting for Services

- DPH will contract with qualified, licensed hospices to provide service coverage statewide.
- Hospices must meet purchase of service criteria and requirements.
- Contractual maximum obligations are determined annually by the DPH.

## F. Access to the Program

**Costs to the Family.** PPCN services are provided at no cost to eligible children and their families.

**Location of Services.** PPCN services are provided in a setting desired and/or appropriate for the needs of the child and family. The choice of setting is made with the child and family. DPH assumes that most services are provided in the home.

**Referrals.** Referrals to contracted PPCN hospices may be made by the primary care provider and/or other providers, DPH programs, and family caregivers. Families may also self-refer.

### Screening/Intake

- The child's primary care provider will be identified and recorded by the PPCN hospice.
- The child will be screened and assessed by participating PPCN hospices for PPCN eligibility.
- For all families, documentation from a physician must specify the life-limiting condition, but the referral, assessment and services may proceed based on verbal assurances by a referring professional (noted in hospice records) while written documentation is obtained.

## G. Care of the Child and Family

### Available Services

The hospice provides consultation and the following palliative care services, as needed, to the child and family. Services include but are not limited to the following.

1. **Assessment.** Children admitted to PPCN and their families receive a comprehensive multidisciplinary assessment of their physical, psychosocial, emotional, spiritual needs and bereavement risks from participating PPCN hospice staff. This assessment will be done by the nurse and social worker, and any other appropriate staff. The assessment process, including initial family contact, begins within 48 hours of referral.

### 2. Plan of Care for the Child and Family.

- As an outcome of the assessment, within 7 days of referral, providers must develop individualized care plans with the child and family
- Hospices document participation of the child (as developmentally, medically, and otherwise appropriate), family participation, and child and family choice of services in meeting notes and/or by obtaining child and parent signatures on the care plan.
- Within 2 weeks of referral, hospices obtain the signature of the primary care provider on the initial care plan to assure coordination.
- Plans are updated as changes occur, and at least every three months, with family participation and

approval documented.

- A copy is sent to the referring physician at least every three months, if there are changes.
  - Families receive copies of care plans.
  - Services are provided to the child and family consistent with the child's plan of care.
  - A young adult age 18 or an emancipated minor may decline further PPCN services at their own discretion. Family members may continue to receive services.
3. Case Management. Case management includes but is not limited to:
- Collaboration with the primary care and other providers to coordinate care across all settings. This must withstand complex, competing and shifting goals of care. The care plan must ensure that it is consistent with the child's and family's goals, and that the level and type of services provided are determined by the child, family members, and appropriate PPCN members.
  - Consultation with primary care and other providers to provide information about the full range of clinical and educational services and resources available to the child, family and primary caregivers.
  - Collaboration with the primary care and other providers to support and promote the normal growth and development of the child.
  - Upon discharge from the PPCN program, the hospice collaborates with the primary care and other providers to coordinate discharge planning and the use of appropriate community resources when PPCN services are no longer needed or appropriate.
  - A child, discharged from the PPCN program, may be readmitted to the PPCN program should the child once again meet program criteria.
4. Pain and Symptom Management. Consultation is provided to the child's primary care provider with palliative care services offered, as needed, for the child to ensure the most effective management of pain, other symptoms, and common health disruptions such as dyspnea, severe nausea and vomiting, agitation and seizures.
5. Social Services and Counseling. Services include but are not limited to:
- Support, psychosocial education and counseling to the child and family about the child's life-limiting diagnosis, prognosis, psychological stress, fears and anxieties, advance care planning, advance directives, withholding or withdrawing life-sustaining therapies and options for the plans of care including end of life decisions.
  - Counseling for family members, including parents, grandparents, siblings and others providing physical, psychological, social and/or spiritual support for the child
  - Referrals to other community resources and services to support the plan of care and needs of the child and family.
6. Respite Services. Respite services may be provided in the home for up to 48 hours per year.
7. Spiritual Care. Spiritual needs, goals and concerns addressed are documented and support offered for issues of life completion consistent with the child's/family's cultural and religious values. Common spiritual concerns include support in times of crisis and despair, unconditional love, forgiveness, hope, safety, security and legacy. The hospice respects the child's and family's religious beliefs and cooperates as requested with the family's choice of spiritual caregiver.

8. Volunteer Support Services. Non-clinical support services by trained volunteers to the child and family under professional supervision are provided to support the family and child.

9. Complementary Health Services. The hospice may offer complementary health services as appropriate to families. These may include, but are not limited to art therapy, reiki, music therapy, pet therapy, and therapeutic massage. A doctor's order must be obtained before providing these services.

10. Pronouncement of Death. Consistent with the laws of the Commonwealth of Massachusetts, pronouncement of death in the home for any child under the age of 18 must be made by the Medical Examiner. The hospice nurse must call the Medical Examiner at the time of death.

11. Bereavement Services. The PPCN hospice provides bereavement services and counseling to the parents, caregivers, surviving siblings and other family members for up to thirteen months.

12. Emergency Care and Planning.

- The prevention of crises and unnecessary transfers is the goal of PPCN. The hospice provides
- information, education and counseling to the family to prepare them for crises that may occur including unexpected pain and other symptoms.
- The PPCN hospice develops a plan to support the primary care provider in addressing after-hour emergencies.
- Provision for the availability of 24 hour emergency symptom management will be part of PPCN services and care planning.
- The regularly scheduled hospice on-call registered nurse will provide coverage for after-hours emergencies
- If the intensity of the disease process requires 24-hour direct care services and/or on call visits for symptom management, a referral for admission to pediatric hospice care will be discussed and considered by the primary care provider and family.
- The hospice will establish and document a communication plan and procedures to follow to ensure all families and caregivers are aware of PPCN emergency contacts and procedures.

13. Collaborative Care Planning.

- The primary care provider retains responsibility for the management of the child and the plan of care.
- PPCN hospices consult with primary care providers to assure that care plans are developed which consider the child's prognosis, the child's and family's needs and desires, potential problems, interventions, and the type of services to be provided.
- PPCN hospices will hold interdisciplinary team (IDT) meetings every two weeks. Each child's plan of care will be reviewed at least once a month, and more frequently if necessary.

14. Discharge Planning

a. CRITERIA: A child on the Pediatric Palliative Care Network (PPCNN) is appropriate for discharge when any of the following occurs:

- The parent/guardian requests it
- In the professional judgment of the IDT, the decision is made that PPCN services are no longer appropriate

- A decision is made by the family to elect the hospice benefit
- When death occurs
- When the child turns 19.
- When the home is not safe as determined by the IDT
- When the family leaves the geographic area of the provider, in which case a referral will be made to the provider covering the family's new community (if in Massachusetts)
- When changes in the payor benefit would cause duplication of services

b. DOCUMENTATION:

- The IDT documents the reason for the discharge in the patient record.
- A parent is asked to sign the Discharge Form when they wish to discontinue Pediatric Palliative Care or when the IDT has determined that services are no longer appropriate
- It is documented in the patient record that the physician and/or referral source and participating community agencies have been advised of the change in status
- A Discharge Plan is created for the child and family members receiving PPCNN services by the IDT and documented in the patient record and communicated to the family

c. COMMUNICATION:

- When the decision for Discharge is being considered by the IDT, great care must be taken to discuss this status change with the family.
- A member of the IDT is responsible for communicating the status of the Discharge to the physician and/or participating community agencies via phone, email or written correspondence to ensure dialog and ongoing communication.

## H. Provider Responsibility

Community Outreach/Marketing. DPH and PPCN hospices provide information to the community and referral sources about the services offered, who is eligible, and how services may be obtained and reimbursed.

### Medical Records

- The PPCN hospice maintains records of decisions related to care, consent, advance directives, treatments, and alternative choices of care and shares them with the primary provider
- Confidentiality of the medical record is maintained in compliance with state and federal laws and regulations, including HIPAA requirements.
- PPCN providers sign and submit DPH-required confidentiality agreements.

### Quality Improvement

- The DPH PPCN director monitors the quality, effectiveness and cost-effectiveness of the program on an ongoing basis.
- Providers report on a quarterly basis and the DPH PPCN director summarizes monitoring and quality improvement results including provider progress on negotiated outcomes and targets.
- PPCN provides a written evaluation tool for families served by PPCN and referral sources to document their satisfaction with the program.



- Ongoing improvements to PPCN will be made based on monitoring results.

#### Coordination with DPH

- DPH contractual reporting requirements are met.
- The PPCN director is notified within 24 hours if there is a critical incident.
- PPCNN Provider Meetings will be held twice annually. All contracted providers are to be present at these meetings, with representation from at least two disciplines.
- Conference Calls. All scheduled calls must have a representative from each provider who will be responsible for disseminating information to appropriate team members.

#### Virtual Gateway

- Services are to be billed monthly, not later than the 20<sup>th</sup> of the month for the previous month.
- Monthly billing must include completion of the Invoice Assessment in order to be processed for payment.
- UFR designations given by DPH will be used for all provider budgets.

#### Grievances

- The PPCN hospice provides a clear and accessible grievance procedure to families outlining how to voice and resolve complaints.
- The grievance procedure is communicated to families and attached to the initial plan of care.

Ethics Review Procedures. PPCN providers have a forum for the interdisciplinary team to regularly consider ethical issues involved and an ethics committee available for issues that require a higher -level discussion.